Non-Family Caregivers of the African American Elderly: Research Needs and Issues[1]

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Introduction

At the beginning of this decade, changes in the demographic profile of the United States population, and specifically the "graying" of the African American population (Williams, 1990), directed the policy interest of the gerontological community to the long-term care needs of the frail and at-risk African American aged adult. Before that time the informal support system of the African American aged, including both family and non-family supports, had been primary in the provision of services and supports to the African American aged adult (Barresi & Menon, 1990). Changes in population dynamics and the service delivery context, however, have impacted negatively on the family in its caregiving role, thus causing the informal support system of the African American aged to weaken.

Of significance are changes such as: the roles of women, particularly their large-scale participation in the work force historically (Oktay & Palley, 1988; U.S. Census Bureau, 1992; Woody, 1992) and more recently due to welfare reform and other devolution policies (UW Extension, 1999); rising divorce rates (Dickerson, 1997); the impact of migration patterns (Comas-Diaz & Greene, 1994); the general decline in the viability of the family support system (Billingsley, 1990; George & Dickerson, 1995); managed health care; the epidemic nature of violence in urban, African American communities (Randolph, Koblinsky, & Roberts, 1996); and the disproportionate rates of traditional morbidities (Manton & Stallard, 1997), as well as new health problems affecting African Americans, particularly women, such as HIV/

AIDS (Dargan & Williams, 1998). Such changes have resulted in a decline in the pool of available family caregivers relative to African American aged in need, thus necessitating the exploration of various community-based non-family continuum-of-care options. Of particular concern is the development of community-based long-term care options as alternatives to institutional long-term and family-based care.

Much of the extant literature on the elderly has focused on caregiving from a monocultural perspective and as a function of the family caregiving context. Little research to date has focused on the various issues of importance to the caregiver in the non-family community-based setting, and specifically informal non-family caregiving to the African American aged adult. Such a gap in the research profile is critical to the caregiving context of the African American aged, as the non-family community-based living arrangement (for example, the personal care home) has emerged as an alternative care arrangement for the at-risk African American aged bereft of a family caregiver. "Personal care homes may be…available for the African American elder when traditional family networks change, such as when young African Americans migrate out of rural communities leaving little or no family behind, and when family networks break down or do not exist" (Kauffman, Randolph, Drake, & Gelfand, 1987, p. 1). To address this research gap, studies are needed to examine caregiver experiences within the sociocultural context of the personal care home and other community-based non-family arrangements servicing the African American aged adult.

The Caregiving Context of the African American Aged

Various factors or conditions impact on and are significant to the caregiving context of the African American aged, including demographics, functional status, socioeconomic status, informal support, and threats to traditional caregiving roles of African American families and communities.

Demographics. The demographics of the African American aged population is of significance to ethnogerontology, particularly given the implications for service delivery and long-term care planning. As Smith (1990) notes, the population of aged African Americans has increased steadily through the 1980s. Currently, the African American aged comprise the largest segment of minority aged in the United States. According to 1990 figures, 8% of the total population of aged Americans was African American. Recent projections, moreover, indicate the continued growth of this subpopulation of aged adults. It is estimated that the population of African American aged will increase by 243.6% over the next 50 years (National Caucus and Center on African American Aged [NCCBA], 1993). Thus, although there are fewer African American aged relative to the African American population than there are White aged relative to the White population (Smith, 1990), the African American

aged population is expected to increase at a faster pace than the non-ethnic aged population. Population estimates for the year 2050 indicate that while the number of White aged will double from the present figure of 28.0 million to 62.4 million, the number of African American aged will almost quadruple from the present figure of 2.5 million to 9.4 million (U.S. Census Bureau, 1993).

Functional status. As is characteristic of the minority aged, however, the black aged can expect a shorter life expectancy (NCCBA, 1991) and higher rates of mortality, morbidity and disability (Manton & Stallard, 1997) relative to the White aged. As Padgett (1990) notes, "members of disadvantaged ethnic groups have shorter life expectancies, may be functionally old well before age 65, and consider themselves 'old' at age 55" (p. 723). The average life expectancy for African Americans in 1990 was 69 years old as compared with 75 years old for Whites (U.S. Census Bureau, 1993). Interestingly, however, although the African American elderly may exhibit greater functional dependence at an earlier chronological age than the White elderly, the 'crossover phenomenon' effect (Hooyman & Kiyak, 1988) indicates that the oldest-old African American aged adult will experience increased life expectancy relative to their White age-mates (Manton & Stallard, 1997). Nonetheless, "by most measures of general health status, blacks in late life have worse health than whites,…fewer blacks than whites remain independent in activities of daily living and instrumental activities of daily living, …[and]…among community residents, black elderly report a larger number of functional impairments than white elderly" (Smith & Kington, 1997, pp. 122-123).

Socioeconomic Status. Various authors contend that poverty is the most insidious social hazard afflicting the African American aged as it is the stem or cause of other social ills (Murphy, 1991), such as poor health status (Edmonds, 1990; Smith & Kington, 1997). According to Reed (1990), inequity of access and underutilization of health services have contributed to the diminished health of the African American aged. Also, "the African American elderly as compared with the White elderly, are more likely to be infirm, to die (up to age 85), to have chronic diseases at earlier ages and to be more physically limited by these illnesses" (Johnson, 1990, p. 70). This claim has been substantiated more recently in a report from the National Research Council entitled, *Racial and Ethnic Differences in the Health of Older Americans* (Martin & Soldo, 1997).

Unlike other populations, however, for whom poverty is most often experienced with advancing age, for the African American aged, poverty is frequently the result of lifelong patterns of discrimination and disadvantage. Smith (1990) points to the contributing effects of unemployment and underemployment as experienced during the productive years on the condition of poverty in the African American aged. And thus for the population of African American aged adults, the condition of poverty

and/or substandard economic conditions is merely intensified with age. Median income for the aged African American worker amounted to but 67% of that as accrued by the aged White worker. Moreover, the unemployment rate for aged African Americans was 5.3% as compared with 2.8% for aged Whites (NCCBA, 1991).

The African American population has the greatest percentage of elderly living in poverty. According to the Select Committee on Aging (1988) "older African Americans are the poorest of the poor among the elderly and they are among the most impoverished groups in our nation today" (p. vii). And although improvements in the poverty level can be noted, the proportion of African American elderly in poverty continues to outnumber the White elderly by a margin of three to one (NCCBA, 1991). The depressed socioeconomic status of the African American elderly living alone or with non-relatives, however, is particularly compelling. In 1989, 91.1 percent of aged African American females and 78.1 percent of aged African American males living alone or with non-relatives were either poor, marginally poor, or economically vulnerable (NCCBA, 1991).

Informal Support. Consistent with historical trends, informal or familial care to the aged, and particularly the African American aged, is the predominate form of elder care (White-Means, 1993). As Barresi and Menon (1990) note, "it is evident that the major sources of caregiving support for the African American elderly are their informal support networks. Both kin and non-kin networks provide for most of the African American elderly's physical, psychological, and emotional needs" (p. 229). Herbert (1983) notes an increase in the tendency of the Black elderly to share a residence not with other family members, per se, but with unrelated Black aged adults. In her study of informal support to the aged, Cantor (1983) notes the tendency of the Black aged adult to receive assistance from friends and neighbors, as opposed, for example, to an immediate family member and/or a more distant relative. Indeed, for many aged African Americans informal care affords the sole source of support (Bryant & Rakowski, 1992).

Some have suggested that the reliance of the Black aged on a system of informal supports is likely the result of high-level service needs, as evidenced, for example, by depressed socioeconomic status, coupled with limited access to existing formal support services (Chatters, Taylor, & Jackson, 1985). Others have found that the black elderly received more aid from families than did white elders even when socioeconomic differences are considered (Mutran, 1985). Others suggest that this system of informal care is rooted in African traditions (see Rhoads-Holmes & Holmes, 1995, for a review). In contemporary times, many accounts provide evidence of strong sources of informal support and mutual aid provided through neighborhood (Jayakody, 1993), church (Billinglsey & Caldwell, 1994; Billinglsey, 1999), and friendship networks (Rhoads-Holmes & Holmes, 1995).

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Threats to Traditional Caregiving Roles

While informal and specifically familial support is critical to the caregiving context of the African American aged, the viability of the family in its caregiving role is at risk (Perry & Johnson, 1994). As noted earlier, perhaps the most critical change impacting upon the family (in general) in its caregiving role is the large-scale entry of women into the labor force. It has been projected that by the year 2000, 75 percent of women aged 45-54, and 45 percent of women aged 55-64 will be working outside of the home. These predictions are probably underestimated for African American women, who have traditionally been in the work force in large numbers. Moreover, these estimates predate welfare reform policies which will require many African American women who traditionally have not worked outside of the home to do so. Apart from impacting on a caregiver's time and availability, employment may alter one's sense of self. The caregiver, for example, may come to question the notion of filial responsibility (and traditional obligatory roles of informal support) as superseding self-actualization and commitment to oneself (Day, 1985).

The effects of migration have also threatened the viability of the Black family in its caregiving role. The exodus of Black Americans from the rural south to the industrial north that characterized the early to mid-1900's was disruptive to the family system and by extension the informal care networks (U.S. Department of Commerce, 1986). As Eshelman (1987) notes, "the significance of these migration patterns largely evolves around their selectivity: not all ages or complete families were caught up in the movement to urban areas or to the north, since the industrial pool preferred young men. This had a tremendous impact both on the community left behind and on the community into which Blacks migrated. It affected family life by disrupting the nuclear family and by geographically separating extended-family ties" (p. 187). Migration may thus have impacted the caregiving context of the Black aged by furthering reliance on the non-family caregiver (Kart, 1990).

Several demographic factors also threaten traditional caregiving roles. Smith (1990) notes an increase in the proportion of never-married aged and a decline in the fertility rates of African American women. There has also been an increase in the divorce rate among African Americans resulting in a concomitant increase in single parent (female-headed) households (Dickerson, 1997). Johnson (1990) notes an increased likelihood that the African American aged adult will outlive a spouse and/or an adult child. The incidence of public health problems such as HIV/AIDS and community violence have resulted in increased deaths among younger African Americans. Such demographic changes impact negatively on the status of the African American aged by fostering a reduction in the pool of available caregivers. Moreover, according to Barresi and Menon (1990), "the informal support networks, both kin and non-kin, of the African American elderly tend to be willing but unable to

provide for the needs of their elderly members" (p. 234). Thus, while "it has been traditional for kin and other members of Black communities to take part or full responsibility for elderly members whose infirmities have become so disabling that they can no longer care for themselves (Watson, 1990, p. 51), these demographic changes suggest that the potential of the African American family to further absorb the elder caregiving function is limited.

Moreover, the minority aged have for some time been generally underrepresented among formal supports such as institutions of long-term care; therefore, such formal supports have not traditionally provided a fully viable caregiving alternative for the African American aged (Select Committee on Aging, 1985). Traditionally, the African American aged has been characterized as comprising 8 to 11 percent of the national elderly population, but by comparison, less than 3 percent of the nursing home population (Clavon, 1986). Also, according to Hines-Martin (1992), rates of institutionalization for African Americans remain less than that for Whites with home care playing a greater role.

In this context, the personal care, or adult foster care home, a non-family community-based living arrangement, has emerged as an alternative care arrangement for the at-risk Black aged bereft of a family caregiver. As an alternative living arrangement for the Black aged adult, the personal care home is best understood in relation to the continuum of care model. According to Lawton (1981), the various community-based care options may be conceptualized as a continuum ranging from independent living in the residential setting to dependent living in the nursing home, or total care facility. Indeed, as the author notes, "the nature of the continuum is such that the degree of support required by the individuals living in each type of housing roughly increases toward the institutional side" (Lawton, 1981, p. 61). However, the range noted suggests increasing support, in fact the continuum is multidirectional in nature, thus reflecting the changing and variable service needs of the at-risk adult population (Dunkle, 1983).

In the continuum of care context, the personal care residence is defined as a high support facility providing residents with three or more of the various physical (ADL) and instrumental activities of daily living (IADL) including, bathing, dressing, shopping, and financial management (Lawton, 1981). Personal care homes fall under the broader category of adult care homes, defined as "community residences which provide room, board, 24-hour supervision and personal assistance to physically and/or emotionally impaired adults who cannot live alone, but do not need skilled nursing care" (Reisacher, 1992, p. 22). For purposes of their study, personal care homes were defined by Kauffman et al. (1987) to include a private residence providing board and care, supervision, and assistance with ADL and IADL to six or fewer unrelated elderly clients.

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Research Needs and Issues

Although caregiving in the non-family community setting, and specifically the personal care home, provides an alternative care arrangement for the at-risk aged adult, little research has addressed this caregiving context for African Americans. Thus, studies are needed to explore the gap in the research literature specific to the non-family caregiving context of the African American aged. Of particular interest should be the relationships between selected caregiver background variables, caregiver objective care demands, and caregiver burden.

Various empirical and theoretical underpinnings specific to the caregiving context of the Black aged should be considered as they shape the conceptual frameworks of research studies in this area. Such constructs as double jeopardy, diverse life patterns, and age as a leveler are representative of the varying perspectives common to the research literature. Double jeopardy, or multiple hazards, is the notion that the minority aged are subject to the additive, or synergistic, effects of both ageism and racism (Dowd and Bengston, 1978). As a research construct, double jeopardy has been modified to include such variants as triple jeopardy (for example, jeopardy based on age, race and sex) and quadruple jeopardy (for example, jeopardy based on age, race, sex and geographic location). Significantly, however, regardless of the variant, the concept of comparison, and specifically the comparison of minority to non-minority aged, is central to the multiple hazards perspective (Kart, 1990).

Unlike double jeopardy, the concept of diverse life patterns deemphasizes the notion of intergroup or race-by-race comparison in gerontological research (Stanford, 1990). The diverse life patterns construct is unique in that intergroup differences are not the subject of study, but are rather assumed. According to Taylor (1985), for example, such a perspective is critical to an understanding of the informal supports of the Black aged as it is revealing of the diversity and heterogeneity within the Black caregiving experience apart from intergroup, or interracial differences.

The concept of age as a leveler, a counter-perspective in gerontological theory, must also be considered. According to Stanford (1990), age as a leveler is the contention that "as people age there is a tendency for the social, physical, and economic dimensions of their lives to become more similar, regardless of their ethnicity and race (p. 36)." And thus contrary to the notion that aging in ethnic populations is associated with increased adversity, or a condition of multiple hazards, age as a leveler is the contention that advancing age nullifies the effects of discrimination and inequality (Hall, 1987). Interestingly, the notion of age as a leveler is not inconsistent with the concepts, as noted, of assimilation and homogeneity among the aged population.

These various constructs are supportive of the ethnogerontological perspective. How-

ever, little empirical testing of the constructs can be noted in the research literature. And, where evident, only mixed support can be noted. Also there is little ethnogerontological research, tempering the multiple hazards model with a focus on the strengths of the ethnic aged. According to Padgett (1990, p. 723), "we should not fall into the 'victimization' trap, focusing only on problems and deficits and ignoring the overwhelming evidence of adaptive strengths displayed by ethnic elders in marshalling personal and social resources under trying circumstances." Focusing on the diverse life patterns construct as a guide in the study of the Black aged, while drawing on the multiple hazards perspective for its context relevant value, would be instructive.

"It is indeed appropriate that scientists and professionals better understand the needs and resources of Black older Americans in an effort to aid them in coping with the increasing demands and challenges of personal aging experiences and those of an aging contemporary society" (Harel, McKinney & Williams, 1990, p. 132). Given the concomitant absence of burden studies in non-family caregiving populations (Reisacher, 1992), the analysis of burden in caregivers to Black aged adults in the personal care home setting is also particularly relevant if the breakdown of the caregiving relationship is to be avoided. Preservation of the personal care home option is critical to the service needs of the African American aged, moreover, given the absence of competing long-term care alternatives.

Therefore, studies are needed to provide the gerontological community, and specifically planners, policy-makers, and service professionals, with insights into the community-based caregiving context of the Black aged adult. An understanding of caregiver informal supports, as well as the potentially additive effect of carereceiver informal support as it impacts the caregiver role is sorely needed. Future research, for example, might address the impact of multiple and/or memory impaired carereceivers on the experience of caregiver burden in the personal care home setting. Longitudinal research on caregiving to the African American aged in the personal care home setting is also needed to assess burden as a function of time.

Future research might also explore respite care as an intervention vis-a-vis caregiver burden in the personal care home setting. Such insights will increase our understanding of home-based services as a continuum of care alternative for the at-risk Black aged (Johnson, 1990), and specifically the Black aged adult bereft of a family caregiver (Gerace & Noelker, 1990). Additionally, such insight will guide the formal support sector in its effort to complement and fortify the informal support system critical to the caregiving context of the Black aged adult. Knowledge of the correlates of burden and the assistance needs of the non-family caregiver will guide service professionals in the selection and implementation of interventions to bolster the caregiving relationship, including for example, respite, homemaker ser-

vices and caregiver training. As such, home-based services for the African American aged adult bereft of a family caregiver might be preserved and strengthened through the utilization of existing social networks. Now, more than ever before, due to the changing demographics and social policy contexts, this advancement in our knowledge base is needed to ensure a quality life for some of the most vulnerable Americans.

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